

2006 ANNUAL REPORT

The Kleine-Levin Syndrome (KLS) Foundation continues to make progress in raising awareness of KLS in the international medical community and amongst the public, supporting those affected by KLS and promoting medical research.

The Foundation's activities and achievements during 2006 include:

Research Progress

The Foundation continues its major effort to support research on the cause and treatment of KLS. Current research programs are focused on possible genetic, viral, autoimmune and environmental causes of KLS. Tentative results this past year from the Stanford University Sleep Center, under the direction of Dr. Emmanuel Mignot, include:

- 1) finding of an increased prevalence of KLS in the Jewish population, suggesting a possible genetic predisposition;
- 2) identification of multiple cases of KLS within families, also suggesting a genetic predisposition, although shared environmental effects cannot be excluded;
- 3) establishment of a collaboration between Stanford University and University of California SF to collect clinical samples and, using cutting edge research techniques, investigate a possible viral involvement in KLS and
- 4) completion of a study showing a lack of association of KLS with HLA (an autoimmune disease marker).

Some of these findings have been submitted for publication in a high impact medical journal. The Stanford research lab hired a Clinical Research Assistant to join the growing scientific team and is collaborating with renowned labs at UCSF and hospitals in France (Hôpital Pitié-Salpêtrière, Paris) and in Israel (Sourasky Medical Center, Tel Aviv).

KLS Research Symposium

The first medical symposium on KLS was held as part of the Associated Professional Sleep Societies (APSS) Annual Sleep conference in Salt Lake City, Utah on June 19, 2006. APSS is a joint venture of the American Academy of Sleep Medicine and the Sleep Research Society. Over 5,000 sleep medicine physicians, researchers and professionals from around the world attended this five-day event. The symposium on current KLS research, entitled "New Developments in Kleine-Levin Syndrome" featured talks by physicians from the US, France, Israel and Taiwan. In order to maximize this opportunity for scientific exchange, the KLS Foundation hosted a dinner and discussion on the current and future directions in KLS research for the symposium presenters and those interested in KLS.

Web Site

The KLS Foundation web site is a valuable source of information and a major means of communicating for KLS patients, families and the medical community. This year it has been updated to a new, more user-friendly format. New content has been added, such as research updates, a list of doctors familiar with KLS, sections about educational accommodations and disability rights for KLS patients, "KLS in the News" and other important Foundation information. There are currently more than 500 KLS patients and family members registered on

the Foundation web site, and the message board chat room has been helpful to many seeking information about KLS.

KLS in the Media

Educating the public about KLS is an important goal of the KLS Foundation and the Foundation has been active in promoting media coverage of KLS. National television news shows including ABC's "Primetime," CNBC's "The Big Idea with Donny Deustch", CBS's "The Montel Williams Show" and CNN's "Paula Zahn Now" aired stories about KLS this year. Other US and international television networks continue to express interest about producing KLS segments. The KLS Foundation is looking for additional volunteers who are willing to participate and share their KLS stories.

The Cleveland Jewish News ran a feature story about KLS featuring two KLS patients from Boston, Massachusetts in a special health section on October 13, 2006. The Weekly Reader Current Science magazine, a science weekly reader for elementary school students, ran a story about KLS in the October 2006 issue featuring a patient from Placentia, California. The Lancaster News ran multiple stories of a KLS mother's efforts to raise funds and awareness about KLS.

Fundraising Report

KLS Foundation members have organized local fundraising events including a sponsored runner in the New York City Marathon, social fundraisers with raffle draws, and educational programs at community schools which later led to fundraising drives undertaken by the students. These grassroots efforts educate the public about KLS as well as raising important funds for the foundation's research initiatives.

The Foundation has begun soliciting corporate donations and received its first corporate gift this year from CRA International, Inc. In addition, multi-year research grants have been submitted to government funding sources by our academic collaborators in order to expand research possibilities.

Fundraising efforts raised approximately \$64,000 in 2006. The Foundation continues to allocate over 95% of donated funds to directly support research efforts, with less than 5% used for Foundation administrative needs.

Looking Forward

In the upcoming year we will be focusing our efforts in the following areas:

- continuing to financially support the research groups, and helping to identify and refer new KLS cases to the research teams
- fostering new research in other laboratories
- increasing the exposure of KLS information to the medical community through participation in conferences and professional events
- seeking additional media opportunities to facilitate the spread of information about KLS to the public
- increasing ongoing fundraising efforts through renewed solicitation drives.

- continuing to be a source of comfort and information to families who contact us after a loved one is diagnosed with KLS.

The KLS Foundation continues to look for dedicated volunteers and potential board members who are willing and able to donate their time and skills to help the Foundation grow by assisting with fundraising, grant writing, publicity, website design, or general support. Please contact the KLS Foundation if you can request funds through your company's charitable giving program or if you are interested in participating in any of our efforts.

Thank you for your continued support.